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ABSTRACT

This theme issue presents personal perspectives and approaches to self-advocacy from individuals who are deaf-blind. Individual articles are: (1) "Self-Advocacy: Attaining Personal Stature" by Michelle J. Smithdas; (2) "The American Association of the Deaf-Blind: A National Consumer Advocacy Organization" by Jeffrey S. Bohrman; (3) a description of the Usher Syndrome Group of the Helen Keller National Center; (4) "The Making of a Self-Advocate" by Winnie Tunison, a deaf person with Usher syndrome; (5) "An Open Letter to the Deaf Community: We Have Usher Syndrome" (by nine individuals); (6) a checklist titled "Do You Encourage Self-Advocacy in Youth Who Are Deaf-Blind? Questions for Service Providers, Families, and Friends"; (7) "Strategies for Enhancing Self-Advocacy with Young Adults Who Are Deaf-Blind" by Lynda L. West et al.; and (8) a list of resources (publications, newsletters, and organizations) for self-advocacy. (DB)

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HKNC TAC NEWS

TECHNICAL ASSISTANCE CENTER

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SELF-ADVOCACY: ATTAINING PERSONAL STATURE

By Michelle J. Smithdas

Today, all around us, we see and hear examples of self-advocacy. Even so, questions surface: What does it mean? When should it be used? Who should use it and why? To me, self-advocacy is a process by which individuals strive to attain their rights as human beings and gain equal opportunities for employment and independent living as well as freedom to choose a desired lifestyle. Self-advocates must speak up and let others know their wants and needs, making it clear that they have the same right to use their potentials and achieve happiness as anyone else. For those of us who are deaf-blind, it is especially important to be self-advocates because we are a small group and are often overlooked by the public. The dual disability of deaf-blindness creates special problems in communication, mobility and everyday living for which we need to be self-advocates, at times, in order to overcome these problems.

To highlight the importance of self-advocacy, this issue shares personal perspectives and approaches to self-advocacy from individuals who are deaf-blind.

We need others to help us fully participate in daily activities and achieve our goals. Our task as self-advocates is to let others know how they can help us participate more fully and accomplish the tasks which will lead to our fulfillment.

As an example, let's take one common activity—shopping. We all need to shop for groceries, household goods, clothing and other personal items. We often need assistance when doing these daily activities. It is important for the deaf-blind individual to let any person providing assistance know how to communicate in a way we understand. If alone, we must play the self-advocate by instructing the shop clerk how to communicate with us. If we go shopping with a friend or a paid helper, we must tell the person just what kind of help we want and need and describe as specifically as possible what we want: "I want to buy long-sleeved winter blouses in solid colors to match these skirts. Can you gather some and describe them to me?" In this case, self-advocacy is critical because the deaf-blind woman needs to be assertive and explain what is wanted and needed both for effective communication and successful completion of the activity. We must become self-advocates and let those helping us know clearly how they can be of assistance.

Self-advocacy is also emphasized at the annual conventions of the American Association of the Deaf-Blind (AADB), which many deaf-blind individuals (members and non-members) attend. At the week-long AADB convention, many support persons who are not deaf-blind volunteer to assist in any way they can to enable the deaf-blind participants to enjoy the convention week. (Volunteers may have limited experience with people who are deaf-blind or they may be interpreters with more extensive deaf-blind experience who are known as Support Service Providers or SSPs.)

As at many conferences, AADB participants

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HKNC-TAC's purpose is to provide national training and technical assistance to education programs and adult agencies providing school-to-adult-life transition services to youth with deaf-blindness.

Project Director
Jane M. Everson, Ph.D.

Assistant Project Director
Kathleen McNulty

Project Coordinator
Theresa Carr

Program Associates
JoAnn Enos
deVergne Goodall
Joan Houghton
Janet Steveley

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Editor, Theresa Carr

Contributor to this issue
Jeffrey S. Bohrman
Theona Chioccioli
Syble Harrison
Rosenda Herrada-Benites
Beverly Kesner
Janice Lejeune
Frank Levine
Joey Lugo
Ilene Miner
Michelle J. Smithdas
Andrew Stender
Winifred Tunison

Layout and Design
Corcoran Communications

regard this time partly as a vacation. But it is most importantly a time for learning and understanding the problems and frustrations of deaf-blindness and sharing ways of coping and overcoming them with creative problem solving. It is also a time for fun with old and new friends. Much self-advocacy is involved as, initially, many volunteers may not know how to assist the deaf-blind individual to enjoy and participate in this event.

Speaking Out on Our Own Behalf

For example, individualized interpreting is needed at meetings and workshops, so the deaf-blind individual must explain to the interpreter how to relay information. It is also up to the deaf-blind participants to choose tours or activities in which they wish to participate, to request that menus be read to them and that specials be described in restaurants, and to ask that places they are touring be described. Deaf-blind participants are very appreciative for all the assistance given by volunteers, and volunteers often say that they learned much about the deaf-blind population from the experience.

The deaf-blind person travelling alone is often frustrated when advocating for his or her needs with strangers who do not understand or respond. On a recent trip from New York to California, I turned to the passenger in the next seat to let her know that I was deaf-blind and that she could help me by printing large block print letters in the palm of my hand. I hoped she would understand and say "Yes." Then I would say "Good" and take a nap. Instead, we spent the four and one-half hour flight chatting via block print! It was fun, and both of us gained from the experience. She wanted to learn the manual alphabet, but found palm-printing easier and faster. She seemed to enjoy being able to talk with me and describe what was on my tray when dinner was served. For all of us, it is a wonderful feeling when you meet people who try to be helpful and friendly by learning to communicate in a new way.

Deaf-Blind People Are Being Understood and Accepted

While most people will not come in contact with deaf-blind people often, and a single deaf-blind person may not have a wide impact on the public, groups of deaf-blind people can and do. Organizations such as AADB, which holds its conventions at various sites in different states, local groups of the deaf-blind in different communities and states, agencies serving the deaf-blind, the deaf, and the blind, and colleges and universities with special education programs and supports can all help to develop a strong sense of teamwork through advocacy. It is exciting to realize this is happening in many places and that deaf-blind people are being understood and accepted, and are developing long-lasting friendships in the mainstream of society.

By working together we are making self-advocacy a natural and enlightening process that continues to help deaf-blind people attain the self-worth and personal stature to which every person is entitled.

Michelle Smithdas is an instructor in the Communications Department at HKNC.

The American Association of the Deaf-Blind: A National Consumer Advocacy Organization

By Jeffrey S. Bohrman, Ph.D., President AADB

The American Association of the Deaf-Blind (AADB) is a national consumer advocacy organization. Its tag title is "Expanding Communication With Deaf-Blind People—A Joy and Necessity Of Life." A non-profit organization, AADB is incorporated and has over 600 members who are deaf-blind as well as other concerned individuals.

AADB Founded in New Jersey in 1937

Initially, AADB was a correspondence group where the people who were deaf-blind could write to each other sharing ideas, problems and dreams. The AADB is organized for the purpose of advancing the economic, educational, and social welfare of persons with deaf-blindness as well as improving morale among deaf-blind individuals.

People who are deaf-blind share the same pleasures and experiences enjoyed by others—social, professional and recreational. They have tremendous talents and potential capacities for contributing to their own well being and to their communities. The mission of the AADB is to assure that a comprehensive, coordinated system of services is accessible to all persons who are deaf-blind, enabling them to achieve their maximum potential through increased independence, productivity and integration into the community.

The first AADB national convention was held in 1970 in Ohio and, except for two years, has been held annually since. To commemorate Helen Keller's birthday, these conventions are usually held during the week of June 27th. Due to the high cost of providing interpreters, they are generally held on college campuses because interpreters can donate their time and skills in return for lodging and meals.

For individuals who are deaf-blind, it is an unique opportunity to interact with each other. A series of workshops, often run by individuals who are deaf-blind themselves, are held as well as daily tours of places of historical and cultural interest. The annual conventions are open to everyone including individuals who are deaf-blind, friends, professionals and families. Young adults are encouraged to come; however, child care is unavailable for younger children.

This year's convention will be held on the campus of University of North Carolina at Greensboro, June 11 to 17, 1994. The theme is, "Caring for Ourselves: Facing the Challenges and Changes." For further information and registration, please write or call the AADB home office as noted at the end of this article. The deadline for registration is June 1, 1994.

Membership in AADB

Membership in AADB is open to individuals who are deaf-blind and other interested people. Individuals who are deaf-blind do not necessarily have a total lack of both hearing and vision. Many members have a partial hearing and/or visual impairment. They may have enough hearing to understand speech, especially when using a hearing aid, and may have some usable vision with or without corrective lenses. Interested individuals include professionals (educators, rehabilitation personnel, interpreters, etc.), family members, and friends. Members receive the "Deaf-Blind American," AADB's quarterly publication printed in large type print or braille, which includes information on the latest technical devices for communication, mobility, daily living, education, editorials, and human interest stories. Membership dues are $15 per year and may be sent to the AADB home office.

For further information on the organization, membership and convention, please write to:

AADB
814 Thayer Avenue, Suite 300
Silver Springs, MD 20910.
TTY number: (301) 588-6545, FAX: (301) 588-8705

Advocating for Our Needs: HKNC's Usher Syndrome Group

At the Helen Keller National Center (HKNC), many of the resident clients with Usher syndrome, Type I, have identified a need for a support group which meets regularly in order to discuss a variety of issues they choose. From the onset, the participants were actively involved in the planning, preparation, and format of their group. Their requests are clearly and assertively stated, and they describe a feeling of strength from planning the schedule and preparing group activities. The group is open and lively. Participants share experiences and argue their points. They help each other. They request information.

Over time the participants have raised many common experiences and issues: growing up in a hearing family; how they found out about their diagnosis of Usher syndrome, Type I; the effect of the diagnosis on the family; and the effect of the diagnosis on their life, work, and social involvements. The participants have also requested specific information about genetics: how they acquired Usher syndrome, and the possible effects on family members. Concerns were also expressed about children and grandchildren, as well as old age and abandonment.

Guest Speakers for Group

To meet the group's requests for more information, HKNC staff helped the group secure guest speakers for some meetings. Speakers have included HKNC staff such as Sr. Bernadette Wynne, who clearly and empathetically described the progressive visual loss associated with retinitis pigmentosa (RP). Others speakers come from out-of-state, such as Sandra Davenport, MD, a geneticist specializing in Usher syndrome. With her open and warm manner, she spent hours using tactual materials to carefully explain the genetic transmission of Usher syndrome.

One important issue, interpreting, affects the format of the group. As the "window" of vision for a person with Usher syndrome becomes smaller and smaller, communication becomes more and more limited, first to one-to-one sign language communication and eventually to tactual sign language only. Because of each member's individual vision and communication needs, the kinds of interpreting requested include one-to-one tactual interpreters, visual interpreters seated far away, and visual interpreters seated close by. In a support group this varied, support staff must be able to meet the interpreting needs of each participant. It makes for a very full room each week!

Excitement of Group Communication

Imagine a group of people used to relying on one-to-one communication, now having enough interpreters to allow conversation to occur among all six or seven group members! Group members express both a desire to communicate with each person on a personal level, as well as a desire to communicate with more than one person at a time. The opportunity to talk to seven people and have them all respond was overwhelming! Ground rules about whether to address the whole group, several people in the group, or just one person are left to group members; all support staff do is provide the necessary catalyst, interpreters.

Support group membership is open to anyone with Usher syndrome, Type I. Participants have the option of joining when they arrive at HKNC and usually remain with the group until they leave. The group is dynamic: new participants bring new experiences, concerns and ideas. It is an ongoing and amazing exploration of the potential of self-advocacy.

HKNC's Usher Syndrome Group is jointly facilitated by Ilene Miner, CSW, a clinical social worker at HKNC and Winnie Tunison, a teacher intern at HKNC with Usher syndrome, Type 1. The article on page 6, "An Open Letter to the Deaf Community: We Have Usher Syndrome," was written by members of the Usher Syndrome Group.

The Making of a Self-Advocate

Winnie Tunison, a strong believer in the importance of self-advocacy is often asked about her experiences as a deaf person who has Usher syndrome. In the photo below, with interpreter Suzanne Dooley, she speaks to the Friends of the Helen Keller National Center, a volunteer support group of community leaders from Long Island, New York.

By Winnie Tunison "When I started to lose my vision I was about 27 years old, and it's been progressing...to the age of 40. At 27, I had night blindness and reduced fields. As time went on, from about 35 to 40, I had many friends, but they didn't know what to do with me. When I was between 41 and 42, some friends invited me to go to another Deaf Club and make a speech to explain how I feel about them not talking with me. I talked for an hour and a half about myself and my feelings and what I wanted from other deaf people.

I explained to them about Usher syndrome, retinitis pigmentosa and how people feel when they are losing their vision. I also explained how to communicate tactually. I told them that when I go to the deaf club, that I'm not a snob because I don't come up and start talking. My husband can't tell me the names of everyone who is there because there are so many deaf people attending. I asked them, please, if you see me, come to me and say 'hi.' Tell me your name and we can chat. Then they better understood what to do. Also, I told them that they don't have to feel obligated to stand and talk with me for a long time. If they see someone they want to talk to, tell me who else is there. I'll say I want to talk with one of those other people too. Then bring me over to the other people; I'll talk with them.

After my speech, many people came up to me and said, 'I understand now. I really understand how you feel.' Now they felt confident, while before they had been afraid to come forward, because they didn't know what to do with a deaf-blind person. That's why they stayed away from me. After I spoke, I had many more friends.

I think I gave them some insights about deaf-blind people, so now they know how to communicate and feel comfortable with me...I feel it is important to be assertive. In the past, I became upset that people were nervous and embarrassed to speak with me. Now that I am assertive, I find that people feel more comfortable with me so I can chat with them. At the end of a conversation, I often ask what they thought of talking with me. And they'll say 'It's fine; it's even fun!' I know they're a little nervous, but after the initial nervousness they feel better. I really enjoy being with my friends again!"

An Open Letter to the Deaf Community:

(This article was written by several members of the Usher Syndrome Group, which was described in the article on page 4. The authors are: Theona Chioccioli, from PA; Syble Harrison, OK; Rosenda Herrada-Benites, MD; Beverly Kesner, OH; Janice Lejeune, LA; Frank Levine, GA; Joey Lugo, PA; Andrew Stender, PA; Winifred Tunison, NJ.)

We are deaf people with Usher syndrome, Type I, who grew up in the Deaf Community and who now have significant visual loss. We don't spend enough time with our old deaf friends any more, although we wish we could. We decided to tell you about our Usher syndrome and how it has affected us. We also would like to give you some tips for communicating with us and make a few requests that will make our lives easier.

There were six of us who met weekly here at Helen Keller National Center for several months to talk about issues related to our Usher syndrome; some of us have already returned to our home states and new people have joined us. This article comes out of our meetings together. Since we came from different parts of the country, we didn't know each other before arriving here. We also come from different backgrounds, but we have become good friends brought together by our need to learn new skills.

What is Usher Syndrome?

Usher syndrome is a genetic condition comprised of congenital deafness and retinitis pigmentosa. For us to have Usher syndrome, both of our parents must have had the recessive gene for it. If only one parent had the gene, we would not have the syndrome although we might have been carriers. Usually the retinitis pigmentosa is not diagnosed until adolescence or later.

We have a problem with the retina, the part of the eye that captures the light. The cells start to die and our eyes don't work well anymore. Each of us is different. We have different vision, and different rates of loss. We started noticing problems at different ages. There are however certain common aspects to what happened to us.

How We Experience Our Eye Problem

First we started to lose peripheral vision which means not only that we can't see to the sides, but also that we cannot see up and down. It also means we have a smaller and smaller window to see things through. Some of us will lose our vision completely, and some of us won't, but there is no way to know who will and who won't lose all their vision. Of the nine authors, five of us have no usable vision and communicate tactually and the remaining four have enough vision to still communicate visually, but need to sit far away from the people we are communicating with to see as much as possible through our "windows."

Another early sign of retinitis pigmentosa is problems seeing at night or in a darkened room. How much we see depends on the available light; sometimes we see more than at other times. Sometimes we look like we are getting around fine, and later in the evening we might need a cane or even a sighted guide. We may be fine and then suddenly reach for a friend's arm when we enter into a dark building. We might be walking outside and then go into a restaurant and ask you to have the menu signed to us because we cannot see the print. We might be signing with you visually and later inside or at night, we might reach for your hand to communicate tactually.

Our Meetings

We have met weekly since February 1992, using interpreters, both deaf and hearing, to meet as a group. During our meetings we discussed our eyes, the genetics of this syndrome, how we found out we had it, guide dogs, programs around the

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country and other useful information, our relationships with old friends, family members, spouses, children, and community groups, and how our lives have changed. We also have guest speakers. We have shared funny stories and sad stories. We wish to tell you some of it.

Our Feelings and Experiences

We, as deaf people, have always treasured our eyes, as we are sure each of you does. If, while you read this article, you can imagine suddenly not being able to read it, or anything at all, or think about not being able to leave your home without planning and possibly getting help, you may begin to understand how we feel with Usher syndrome. The visual loss started slowly, and we had to adjust bit by bit. Ultimately the loss impacted on our lives and we had to change the way we live.

Six of the authors of the Open Letter gather for a meeting of the Usher Syndrome Group. They are (top, left to right) Frank Levine, Andrew Stender, Joey Lugo, (bottom, left to right) Winifred Tunison, Theona Chiocciolí and Rosenda Herrada-Benites. Missing from the photo are Syble Harrison, Beverly Kesner and Janice Lejeune.

Remember that we are exactly the same people we were before we lost our vision with families, spouses, children, grandchildren, jobs, activities, hobbies, friends. Our vision loss impacts on everything. We would like you to understand us better because we have had some bad experiences with you, the Deaf Community.

We Need Your Patience

We notice some of you have no patience with us: when you see a deaf-blind person, you turn away, or try to avoid contact with us. Some of us have been insulted by people who thought that they were teasing us. One member was told that her vision was worse than a horse with blinders on: the person who said that thought it was funny. It was painfully far from being funny.

One of our group mentioned going to the local club, reaching out to communicate and having that person pull her hand sharply away, as if she could catch blindness. We have learned that many deaf people don't like to use tactual sign language: they pull away from us which is insensitive and insulting.

Some of us have sat in our Deaf Club with almost no contact from other club members and our friends for hours. We spend a lot of time alone, and when we come to the club, we are really hungry for contact, discussion, news, chatting and information. We also have ideas and opinions we want to share with you! We don't want deaf people to pull away from us, rejecting us because of our blindness.

Our Thoughts and Suggestions

We would like to explain our communication needs and offer some ideas to help us understand each other better. First, we have to stand some distance from the person we are communicating with so that we can see more of the person's hands, face, and body. Sometimes we ask you to sign small

so that in our tunnel vision we don't lose sight of your hands. Sometimes we have to ask you again and again to stand back, and you think we are making up this problem and you don't want to be bothered. Sometimes you forget to keep your signs small and start signing big again. We are embarrassed to remind you so we just give up and smile and nod as if we understand.

We look like we are clumsy when we trip over things, or spill things we do not see. Some people think we are stuck-up and unfriendly because we don't see them and cannot respond to their waving at us from the sides. Some of our friends think we can see them coming toward us and they grab us to give us a hug and frighten us to death because we have seen nothing before being grabbed! Please touch us softly at first so we are aware that you are there.

When we are sitting with people at a table and someone puts a drink on the table next to us, we need to be informed. We probably won't have seen it there and the next time we move, we may knock the drink over.

Please tell us about things in our periphery that you think we haven't seen. We won't be insulted, and you will save us from a moment of embarrassment or possibly from an injury.

For those of us who communicate tactually, the first thing we need to know is who is communicating with us! Identify yourself when you first touch us. It's strange to have someone touching our bodies and hands when we don't know who it is. Some people like to play a game of "guess who?". If it is a close friend, that is sometimes all right, but for others it is not an all right game; it makes us feel uncomfortable and embarrassed.

Please Sign Naturally

When you approach us, please sign naturally! If you are generally animated, then continue to sign that way. If you usually fingerspell a lot, continue to do it. Many people think they have to sign slowly, simply, and blandly for us to understand. But your sign is part of your personality! We want you to keep that because it is part of you - it is the way that we recognize you.

If you approach us and we are sitting and you are standing, please either sit down with us or ask us to stand up with you. It is important for us to be at the same height for two reasons: it helps in understanding by helping us to mentally place your hands in space and it prevents both of us from getting muscle and arm strain from reaching up or down to communicate.

We like our friends and our family members too to let us know when they enter and leave the house. It is frightening to bump into someone we did not know was there, and it's a waste of time to be looking for someone who has already left.

We know that it may be time consuming to spend time with us because we can only chat slowly and with one person at a time. You are used to talking fast with many people at once. We ask you to be patient with us. You were our friends; don't ignore us or be afraid to communicate with us tactually.

Offer Us Feedback

It helps if you give us feedback while we are chatting by putting your hand under ours—obviously we can't see you nodding your head! If someone else approaches us, you can let us know that someone else is there. If you need to watch them for a minute, let us know. It's polite to sign what the other person is signing to you; after all, if we could see, we would know what they are talking about. Most importantly, if you need to walk away, tell us. There is nothing worse than thinking that we are chatting together, but when we reach out, find that you have left and we are signing to ourselves.

At home we also remind our families to tell us if they have invited friends over in order that we

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aren't surprised by bumping into someone we didn't know was there. Sometimes a family member moves a piece of furniture and forgets to put it back where it belongs or leaves a kitchen cabinet door open creating a hazard for us that causes us to smash our heads.

Losing Vision Means Losing Independence

One of the difficult things about our vision loss is losing independence. We don't like to ask for help but sometimes we must ask for a ride to the store or church, or for a favor of picking up something at the store. We hate to ask. We only wish that occasionally our friends would call to see if we need anything. We won't abuse by asking for help too often. If we do, please tell us. We will pay for any gas you use in driving us someplace.

It is tough to give up the independence we had —driving, shopping, visiting, doing things on the spur of the moment. No one likes to be dependent on others so often. We strive to be as independent as possible.

Our vision loss impacts on our families. They have had to adjust too. For some of us, our time with our families is different now. We miss some of our old hobbies. We miss not getting the news every day. Some of us insist that family members give us the news of the world every day so we can stay up-to-date.

Ask Us Questions

We want you to ask us questions. If you aren't sure of how to approach us or communicate with us, let us know. We are happy to answer questions and we will let you know if we need changes in the communication for better understanding. We want to tell you about our families, jobs, and activities and we want to know about yours. We want to be involved in the life of our community, with the people with whom we have spent our lives. We don't want to be ignored, insulted, left out and hurt. We were your friends. Don't be afraid of us. Don't pity us. If you cared about us before, remember we are the same people we were.

We Miss Our Deaf Friends

We are each an individual with varied needs, but we find ourselves limited more and more to interacting only with other deaf-blind people. With each other we find comfort in sharing communication and other issues. We don't always have to explain our needs to each other, but we want more. We want contact with deaf people who still have vision.

We grew up with you in our deaf world. We miss you. Please take a few minutes to be with us, don't be afraid. We don't like being isolated from the life of the community.

Theona Chioccioli *Syble Harrison*
Rosenda Herrada-Benites
Beverly Kesner *Janice Lejeune*
Frank Levine *Joey Lugo*
Andrew Slender *Winifred Tunison*

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Open out: Open Letter *continues inside.*

Do You Encourage Self-Advocacy in Youth Who Are Deaf-Blind? Questions for Service Providers, Families and Friends

If you work with young people who are deaf-blind, or have friends or family members who are deaf-blind, asking these questions—and answering them—will help you foster their self-advocacy skills and their independence.

1. Have I asked the people who are deaf-blind how I can best communicate with them?

Have I made an attempt to learn their method of communication?

Am I really listening to what is said, or am I imposing my point of view?

2. Do I see real human growth and potential in young adults who are deaf-blind or do I see "disability" and "limitations?"

3. Have I "checked out" my actions, feelings, and language with people who are deaf-blind?

4. Are any of my actions based upon a potential "conflict of interest" or a need to be "controlling" in any way?

5. Do my actions:

- increase the self-respect, self-confidence, self-reliance in people who are deaf-blind, and encourage them to take risks?
- decrease the person who is deaf-blind's dependence on me?
- increase a "peer support" system and encourage leaders who are deaf-blind to take over my role?
- teach people a "process" for making decisions, solving problems, and doing things on their own?
- decrease the chance that I will be seen as a "manipulator?"
- increase the person who is deaf-blind's opportunities to understand and participate in the decisions that affect his or her life?

6. Do my actions promote respect and recognize individual growth as well as group spirit?

7. Do my actions encourage and assist self-advocates in obtaining and understanding a wide variety of information and different points of view so that they can make informed decisions?

Have my actions developed "allies" for the self-advocate's point of view?

8. Do my actions recognize that anger is okay and indeed justified in many instances and encourage people to use anger for positive growth and societal change?

9. Is it okay for people who are deaf-blind to:

- question my point of view?
- work me out of a job?
- tell me that they don't need me and can decide on their own?
- give me negative feedback about what I am doing?
- not see me as an "authority figure?"

10. Do I realize that advisors as well as self-advocates and self-advocacy organizations are "fallible," prone to making mistakes, and having problems just like anyone else and any other organization?

Adapted from materials developed by People First of Washington State.

Strategies for Enhancing Self-Advocacy with Young Adults Who Are Deaf-Blind

Young adults who are deaf-blind should be encouraged to be self-advocates who strive to express their preferences, make choices, take responsibility for their decisions and gain independence by directing their own lives. The following strategies for enhancing self-advocacy provide students with a means of becoming active participants in school and adult service program planning and delivery.

- Reinforce the importance of self-advocacy among students who are deaf-blind. Encourage them to attend and be active participants in the IEP and transition planning process. A student should be aware of and exercise his or her right to attend the meeting, give his or her opinion, have the objectives he or she wants included in the planning meeting.

- During the IEP and transition planning meetings, ensure that forms and processes are explained and presented in a format that the student who is deaf-blind can understand.

- Encourage the young adult who is deaf-blind to express his or her wants and needs. (For sample questions to ask young adults to stimulate future thinking, see article in HKNC-TAC News, Fall 1993, *Students with Deaf-Blindness Participate in Transition Planning: Questions for High School Classes and Support Groups.*)

- Encourage the student to ask questions for guidance but to make up his or her own mind after reviewing the information.

- Ask the young adult who is deaf-blind to think of possible solutions to problems, discussing the positive and negative sides of the problem and each proposed solution.

- Identify opportunities for teaching self-advocacy. Provide practice in self-advocacy skills in various situations such as setting up a class schedule, asking for accommodations needed for a course, meeting a rehabilitation counselor or social service caseworker, and interviewing for a job.

- Help students develop and run their own support group.

- Provide access to adults who are deaf-blind as role models—through guest speakers, letter-writing, and AADB activities.

- Identify specific examples of self advocacy within IEP and transition planning objectives such as situations in which it may be necessary to self-advocate; defining the terms assertive, passive and aggressive; identifying assertive, passive and aggressive behavior as illustrated in various scenarios; stating personal examples of assertive, passive and aggressive behaviors; and responding assertively in given situations.

- The student should be aware of and assume *responsibility* for:
  - thinking about goals for the future,
  - communicating wants and needs with parents and teachers to determine realistic goals,
  - sharing ideas and feelings with IEP and transition team members, and
  - following up on the objectives for which he or she is responsible.

Adapted from (1992) Lynda L. West...et. al. "Integrating Transition Planning into the IEP/ITP Process."

Resources for Self-Advocacy

PUBLICATIONS

Adams, Janice. (1992). **Self-Determination.** In *Proceedings of the National Symposium on Children and Youth Who Are Deaf-Blind.* Reiman, J. & Johnson, P. (eds.) Monmouth, OR: Teaching Research Publications.

Osborn, Jacqueline et al. (1987). **A Self-Advocacy Curriculum for High School Students & Self-Advocacy Curriculum Teacher's Manual**. This set of curriculum materials provides basic instruction for secondary students in the principles of self-advocacy. It includes 15 lesson plans with checklists, suggested role plays and other activities. Available for $10.50 from The University of Kansas, University Affiliated Program, Lawrence Campus, Institute for Life Span Studies, 1052 Dole Human Development Center, Lawrence, KS 66045. (913) 864-4950; FAX (913) 864-5323.

Sauerburger, Dona. (1993). Assertiveness **and Control over One's Life.** In *Independence Without Sight or Sound—Suggestions for Practitioners Working with Deaf-Blind Adults.* American Foundation for the Blind, 15 West 16th St., New York, NY 10011.

West, Lynda L. et.al. (1992). **Transition and Self-Advocacy.** In *Integrating Transition Planning into the IEP Process.* (7-10). Reston, VA: The Council for Exceptional Children.

NEWSLETTERS

NAT-CENT NEWS, published by HKNC in large print and braille, is available free to all readers who are deaf-blind and for libraries. There is a $10 subscription fee for all other readers This publication focuses on topics of interest to individuals who are deaf-blind such as services, aids and devices, human interest, legislation and other news.

Usher Syndrome Family Support is a newsletter for families of people with Usher syndrome. Published quarterly, subscriptions are available for $14.00 a year (USA) or $20.00 outside the USA. Contact Helen Anderson, Usher Family Support, 4918 42nd Ave. S., Minneapolis, MN 55417.

ORGANIZATIONS

To assist in the implementation of the **Americans with Disabilities Act (ADA)**, The National Institute on Disability and Rehabilitation Research (NIDRR) has funded regional disability and business technical assistance centers. For information about the ADA call 1-800-949-4232 Voice/TDD.

Self Advocates Becoming Empowered is a national organization of self advocacy groups. For more information contact Ms. Nancy Ward, P.O. Box 121211, Nashville, TN 37212. (402) 476-0002.

The American Association of the Deaf-Blind (AADB) is the national organization of people who are deaf-blind. It provides advocacy and referrals to help insure independence and integration into the community and sponsors an annual convention. Members include individuals with deaf-blindness, family members, friends, professionals and others interested in deaf-blindness. Contact AADB at 814 Thayer Avenue, Suite 300, Silver Spring, MD 20910. (301) 588-6545 (TTY) and FAX (301) 588-8705. (See article on page 3.)

The **National Coalition on Deaf-Blindness** is primarily concerned with advocacy on the federal level, through informational letters about the needs of individuals with deaf-blindness, individual testimony to congressional committees and congressmen. Membership includes individuals with deaf-blindness, family members, professionals in education and rehabilitation, and other concerned citizens. For information contact Steven Davies, National Coalition on Deaf-Blindness (NCDB), 175 North Beach St., Watertown, MA 02172. (617) 972-7347.

Protection and Advocacy (P&A) Agencies operate in each state to protect and enforce the rights of persons with developmental and mental disabilities. For the designated P&A agency in your state inquire with the National Association of Protection and Advocacy Systems, Inc., 900 2nd St. NE, Suite 211, Washington, DC 20002. (202) 408-9514.

Fall 1994—New Book to be Available

Supporting Young Adults Who are Deaf-Blind in Their Communities - A Transition Planning Guide for Service Providers, Families and Friends

Edited by **Jane M. Everson, Ph.D.**, Project Director, Technical Assistance Center, The Helen Keller National Center for Deaf-Blind Youths & Adults, Sands Point, NY, and Associate Professor, School of Allied Health Professions, The Human Development Center, Louisiana State University Medical Center, New Orleans, LA.

Forward by **Robert J. Smithdas, L.H.D., Litt.D.**, Assistant Director, The Helen Keller National Center for Deaf-Blind Youths & Adults.

Contents:

- Foreword (Smithdas)
- What Happens When Children with Deaf-Blindness Grow Up?: An Overview of Transitional Services (Everson & McNulty)
- Beyond Programs and Placements: Enhancing the Development of Individualized Transitional Services (Everson)
- Supporting Medical and Health Concerns (Armstrong, Carr, Belanich, & Mascia)
- Consumers Speak Out (Carr)
- Perspectives on Transitional Services: Parents Speak Out (McNulty)
- Creating Housing Options and Support Services (Enos, Everson, & Dufresne)
- Working and Contributing to One's Community: Strategies for Including Young Adults with Deaf-Blindness (Everson, Burwell, & Killam)
- Developing Leisure and Recreation Opportunities (McNulty, Mascia, Rocchio, & Rothstein)
- Building Relationships with Friends and Other Community Members (Enos)
- Communication Instruction and Support Strategies (Goodall & Everson)
- Orientation and Mobility Issues and Support Strategies (Cioffi)
- Transitional Services: Implications for Organizational Change in High School Educational Programs (Steveley & Everson)
- Using Adult Services to Achieve Transition Goals and Objectives (Everson & Killam)
- Interagency Approaches to Transitional Services (Rachal)
- Appendices
- Index.

Royalties from *Supporting Young Adults Who Are Deaf-Blind in Their Communities: A Transition Planning Guide for Service Providers, Families, and Friends* will be donated to The Helen Keller National Center for Deaf-Blind Youths & Adults.

Order: Stock #1618—Everson, *Supporting Young Adults Who Are Deaf-Blind*: Approx. $39.00; November, 1994; Approx. 400 Pages: 7X10, paperback

ISBN 1-55766-161-8

Paul H. Brookes Publishing Co., PO Box 10624, Baltimore, MD 21285

Call TOLL-FREE 1-800-638-3775 or FAX 1-410-337-8539

TAC NEWS

HELEN KELLER DEAF-BLIND AWARENESS WEEK

College freshman Eric Randolph and his family have been selected as the poster family for the 1994 Helen Keller Deaf-Blind Awareness Week.

Celebrate with other agencies and programs worldwide by participating in the **Helen Keller Deaf-Blind Awareness Campaign** highlighting the week of **June 19 - 25, 1994**, but continuing throughout the year. *Parent and Family Involvement*, long recognized as a necessary and desirable component of advocating for support services and full accessibility for people who are deaf-blind, is the focus this year.

The Randolphs have been selected as the 1994 poster family for the national awareness celebration. Mrs. Randolph's philosophy has had a strong impact on her family. "Every child should do as much as he or she can, even though there are a hundred reasons we can't do something." Her son, Eric, who is blind and severely hard of hearing, is a college freshman, who loves sports and computers. When asked about his future plans, he confidently said, "I'm leaving my options open..."

To increase opportunities for individuals who are deaf-blind, all citizens, civic groups, libraries, schools and organizations are encouraged to plan state and local activities during the month of June, and especially during the week of **June 19 - 25**. A sample proclamation, a radio public service script, a list of suggested activities, 1994 posters, ad slicks and a press release are available at no cost from the Public Relations Department at HKNC, ext. 325.

HKNC Technical Assistance Center
111 Middle Neck Road
Sands Point, New York 11050-1299
VOICE: (516) 944-8900
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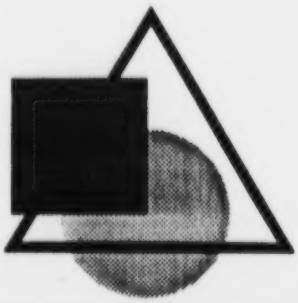

"Every human being has undeniable rights which, respected, render happiness possible—the right to live his own life as far as may be, to choose his own creed, to develop his capacities . . ." **Helen Keller**